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## HMO agrees to pay for ill boy to visit specialist

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Little Jack Zembsch, the 4-year-old with an extremely rare bone condition whose parents have been feuding with their HMO, will get his trip East to see a specialist.

Responses to a Saturday column on the little boy's plight were dramatic. E-mails of support poured in as well as offers of cash donations.

Among the calls was one from a Health Net spokesman, saying the medical insurance company would cover the cost of a visit to see Dr. William Mackenzie, the Delaware specialist at the Alfred I. duPont Hospital for Children that Jack's parents, Mark and Kim Zembsch, want to treat their son.

"We will be ready, maybe as soon as Monday, to pay for Jack to see Dr. Mackenzie," said David Olson, senior vice president of communications for Health Net. The HMO had been saying that a doctor at UCSF could perform the delicate surgery Jack needs to prolong his life.

As encouraging as that news was, however, it is unlikely to settle the contentious disagreement between the Zembsch family and the HMO. Health insurance attorney Arnold Levinson said that he will file a lawsuit Monday and that he was not impressed by Health Net's offer Saturday.

"We appealed this four times," Levinson said. "Why are they all of a sudden approving it now? All they are going to say is that they will fund one consultation with Dr. Mackenzie. We asked for a standing referral so Jack can be under Dr. Mackenzie's care. That's the legal issue."

Olson said the funding would, in fact, "be for consultations. Surgery will be a separate matter."

But he added that funding for an operation would not be a problem if it was determined that it is what Jack requires. "It's in our interest to see that this kid gets what he needs," Olson said.

The real issue of contention is whether or not Jack could get the care he needs from Dr. Mohammad Diab, who is in charge of pediatric orthopedics at UCSF. Olson insists that Diab was willing and qualified to do the rare and complex surgery, even though Jack's condition, metatropic dysplasia, makes his bones soft

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and extremely delicate.

"Dr. Diab said, 'I can do this,' " Olson said. " 'I can take care of this kid.' If we had seen a letter from him that said, 'I can't treat this kid,' it would have been a slam dunk (to send Jack to Mackenzie)."

But Levinson disagrees with the company's interpretation of Diab's statements, and also with the idea that he would be a good choice to perform the surgery.

"The first thing I would ask is how many of these surgeries has Dr. Diab performed?" Levinson said. "Because the answer is zero."

Mackenzie, a recognized authority on metatropic dysplasia, has "been doing this (for) 15 years," Levinson said. The attorney also disagreed with Olson's characterization of Diab's interest in treating Jack himself.

He referred to Diab's report, which Olson faxed to The Chronicle.

In it, Diab says that the Zembsch family wanted to see Mackenzie, "which I believe is reasonable as he has the most experience in this problem in this disease." Levinson concedes that Diab said, "I would be happy to participate" in treatment, including surgery, but will argue that is a far cry from giving Jack the best available care.

But he also believes it is not the best option for the Zembsch family. "We could have a surgeon go in there and do his best," Levinson said. "But they deserve a specialist."

Olson also said Diab never indicated that Jack's condition was so dire that he needed immediate treatment and suggested that Levinson was presenting it in that way to build his case.

Olson called the statements that Jack is in imminent danger "a typical lawyer ploy. There is nothing in the record that indicates that something has to happen right now."

But the Zembschs say Mackenzie warned them that as Jack's spine continues to curve, the risk of it snapping or pressing down on his lungs increases. Kim Zembsch says she's been told Jack's spine is "within a few degrees" of the point when surgery will be an emergency, not an option.

Levinson responds by pointing to a section of Diab's report where he says, "The patient's (spine) is becoming very rigid. While he is young I recommend at least a discussion about (a surgical procedure). I worry that the door is closing, if not has closed, because the spine is becoming so rigid."

Olson also maintained that the Zembschs should have gone to the Independent Medical Review, a panel of doctors who rule on matters of care and are not affiliated with any health insurance company. Patients can take disputes about treatment to the state panel, whose decisions are binding.

Levinson called the panel "totally inappropriate for this situation" because it is used to rule on

experimental procedures that may not have been approved.

C.W. Nevius' column normally appears Tuesday and Saturday in the Bay Area section and on Friday in East Bay Life. E-mail him at [cwnevius@sfchronicle.com](mailto:cwnevius@sfchronicle.com).

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